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A Collective Approach to Death and Dying: An Equitable and Population Health Approach to Advancing End of Life Literacy in Rural Communities

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What does Living Well and Ending Well mean to you?

Objectives

- 1. Identify barriers: Understand rural communities' unique challenges in accessing end-of-life education and resources and explore effective strategies to address these gaps.
- 1. Integrate Planning: Expand the understanding that discussing and planning for the end-of-life is a shared responsibility within a healthy community.
- 1. Enhance Community Initiatives: Provide innovative examples of community-driven approaches to aging in place and preparing for end-of-life, emphasizing creative and collaborative solutions that address population health in a rural community where 27% of the Tillamook County population is 65 years and older.



Population Health ~ Public Health

Social Determinants of Health and Living Well Impact

Death and Ending Well
Living Well ~ Ending Well

Why Death & Dying Are Health Equity and Population Health Issues

Unequal Access to End-of-Life Care

- >Rural, low-income, and BIPOC communities face barriers to hospice, palliative care, and home death options
- Financial burden and lack of care planning increase suffering and reduce dignity

Structural Inequities Influence the Dying Experience

- > Historical trauma, discrimination, and mistrust of medical systems affect care access and decision-making
- > Language, immigration status, and literacy gaps limit informed choice

Dying Well Is Part of Living Well

- > Public health includes the full lifespan—including dying and grieving
- Advance planning and community-based care improve outcomes and respect autonomy

Population Health Includes Grief, Legacy & Dignity

Grief Is a Public Health Concern

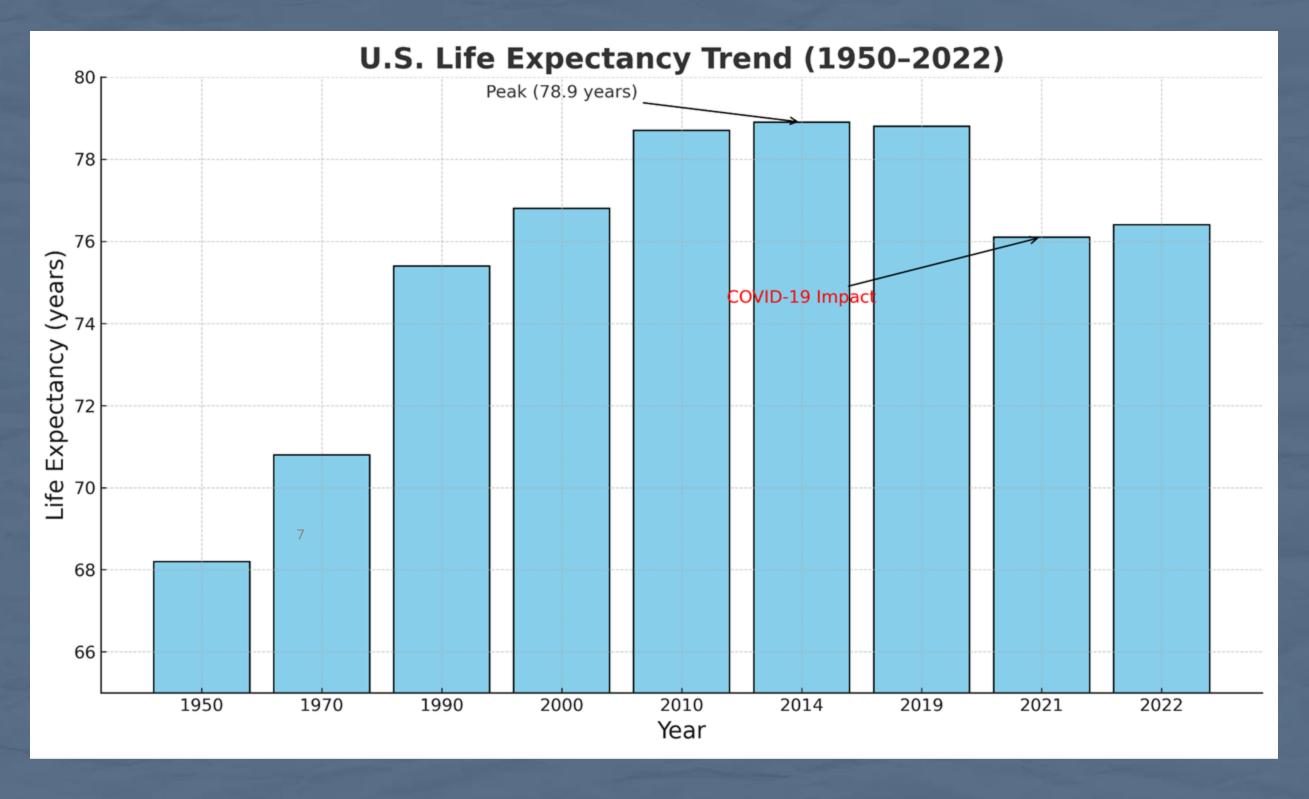
- ➤ Unprocessed grief contributes to mental health crises, substance use, and chronic illness
- ➤ High-death burden communities (e.g., COVID, overdose) need collective support and healing

Health Equity = Death Literacy

- ➤ Everyone deserves culturally respectful, identity-affirming end-of-life care
- ➤ Building death literacy enables informed choices, autonomy, and reduced trauma

U.S. Life Expectancy Trend (1950-

"For the first time in modern U.S. history, adult life expectancy has decreased due to a combination of drug overdoses, suicides, rising chronic disease, gun violence, and the profound impact of the COVID-19 pandemic."



Centers for Disease Control and Prevention (CDC). (2023). National Center for Health Statistics: Life Expectancy Data. Retrieved from https://www.cdc.gov/nchs/nvss/life-expectancy.htm

Woolf, S.H., Masters, R.K., Aron, L.Y. (2021). Effect of the COVID-19 Pandemic on Life Expectancy in the United States. JAMA Network, 326(16), 1632–1634. https://jamanetwork.com/journals/jama/fullarticle/2784350

Pediatric and Adolescent Populations

Compared to prior generations, today's pediatric and adolescent populations are growing up with significantly greater exposure to death and dying — through rising rates of suicide, homicide, mass violence, the opioid crisis, and pandemic-related losses. This shift marks a profound change in the developmental landscape for youth.

Sources:

CDC, Lancet, Everytown, Pew Research, JAMA Network, Common Sense Media

OUR STORY

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VIRTUAL INFO SESSION

Sept 7 | 12 - 12:30PM

Oct 19 | 12 - 12:30PM

NORTH COAST EOL COLLECTIVE

Vision

A Collective Approach to Death and Dying

Values

Acceptance – to be a container for the joy, suffering, and uncertainty of each person's lived experience and relationship with death and dying.

Belonging – person-centered, inclusive, equitable. Each person has a unique lived experience and story within our shared humanity.

Connection – with a servant's heart to listen, bear witness to, and hold the story of each individual and family as a unique and integral part of our shared humanity and sense of place.

Legacy - the invitation to create beauty and meaning from our lived experience and story

Mission

Creating community by connecting people, resources, and experiences to educate and support a holistic approach to end-of-life for individuals and families living on the North Coast.



"Our practice is based on the belief that the North Coast EOL Collective has a shared responsibility to the community by making visible what is too often invisible."



Compassionate Community Model

Communities are empowered to develop initiatives tailored to their local needs, creating systems of care that are more responsive and inclusive.

Is an approach to end-of-life care that seeks to engage the broader community in supporting individuals and families through dying, death, loss, and caregiving. It emphasizes the idea that end-of-life care is not just the responsibility of healthcare professionals but also of the community in which the person lives.



Structure

The North Coast EOL (End of Life) Collective can play a pivotal role in shifting the paradigm from an institutional model of care to a more holistic, community-based, and collective approach to death and dying

Benefit Corporation for Good

Hybrid



"Create unencumbered...."

Services





Meaning Making and Legacy Projects with Co-Founder Carolina Starrett

"We all have a story, it's all in the telling."

- ☐ Health System Navigation
- ☐ Advanced Care Planning
- ☐ Aging and EOL
 - Consultation
- ☐ Grief, Bereavement,
 Traumatic Loss
- ☐ Resource and Referral
- ☐ Legacy Project(s)
- ☐ Death Cafe(s)
- ☐ Education
- ☐ Community Engagement

Individual

Community

Virtual

Home

Community Education and Impact

"I had no idea."

- → CMCA
- → Suzanne Elise
- → Conscious Aging
- → Green and Conservation Burials
- → Legacy and Meaning Making
- → Compassion and Choices
- → Death with Dignity
- → Funeral Rites and Family Rights
- → Fiscal and Legal
- → ACP and POLST
- → Donor programs
- → Music Thanatology/Threshold Choir
- → Grief and Bereavement
- → Hospice and Palliative Care

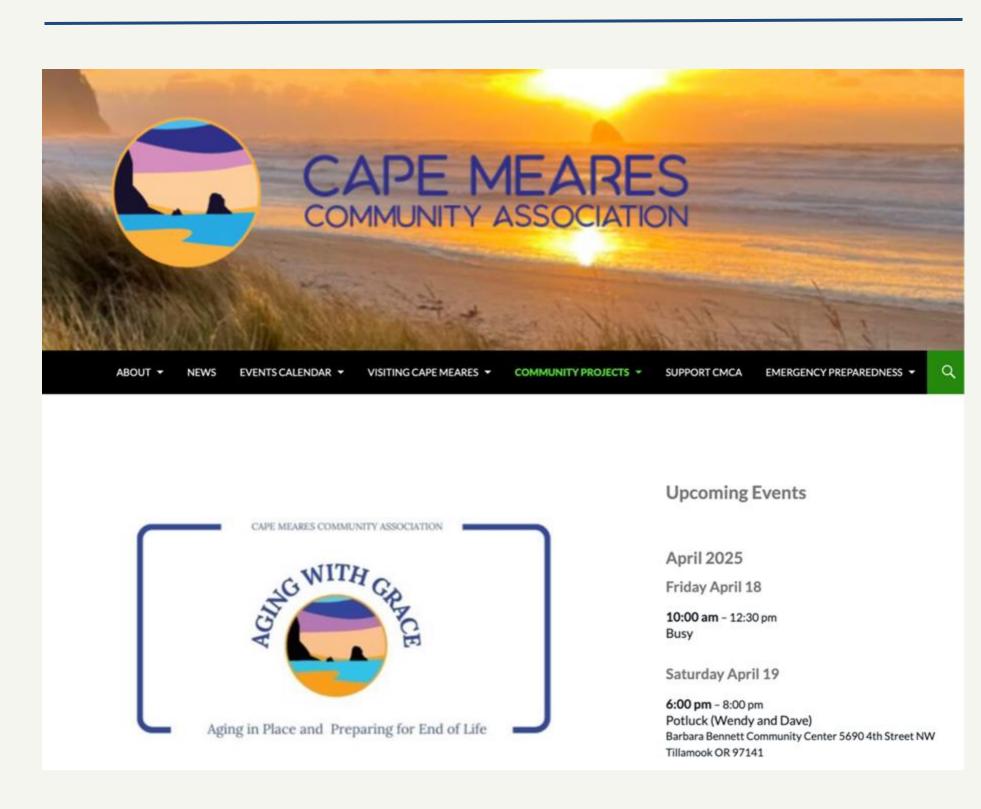
Educational Offerings

Conversation

Consultation

Current Initiatives

- ➤ Cape Meares: Aging in Place and Preparing for End-of-Life
- ➤ Oceanside/Netarts: Modeling Aging in Place and Preparing for End-of-Life
- Accorda Music Thanatology Institute Community-Based Practice
- ➤ 2025 Forum on Rural Health: A Collective Approach to Death and Dying: An Equitable and Population Health Approach to Advancing End⁶ of Life Literacy in Rural Communities
- ➤ Caring for Communities Conversations on Public Health Palliative Care
- ➤ Befriending Transitions: Conversation about Change
- ➤ Death Cafe(s)



Aging with Grace:
Aging in Place and
Preparing for End of
Life



Cape Meares Community Association

The Cape Meares Community

Small coastal community with about 120 full-time residents and no commercial services

15 minutes to Tillamook and Adventist Hospital

Active and well organized community association and strong community spirit of cooperation and caring

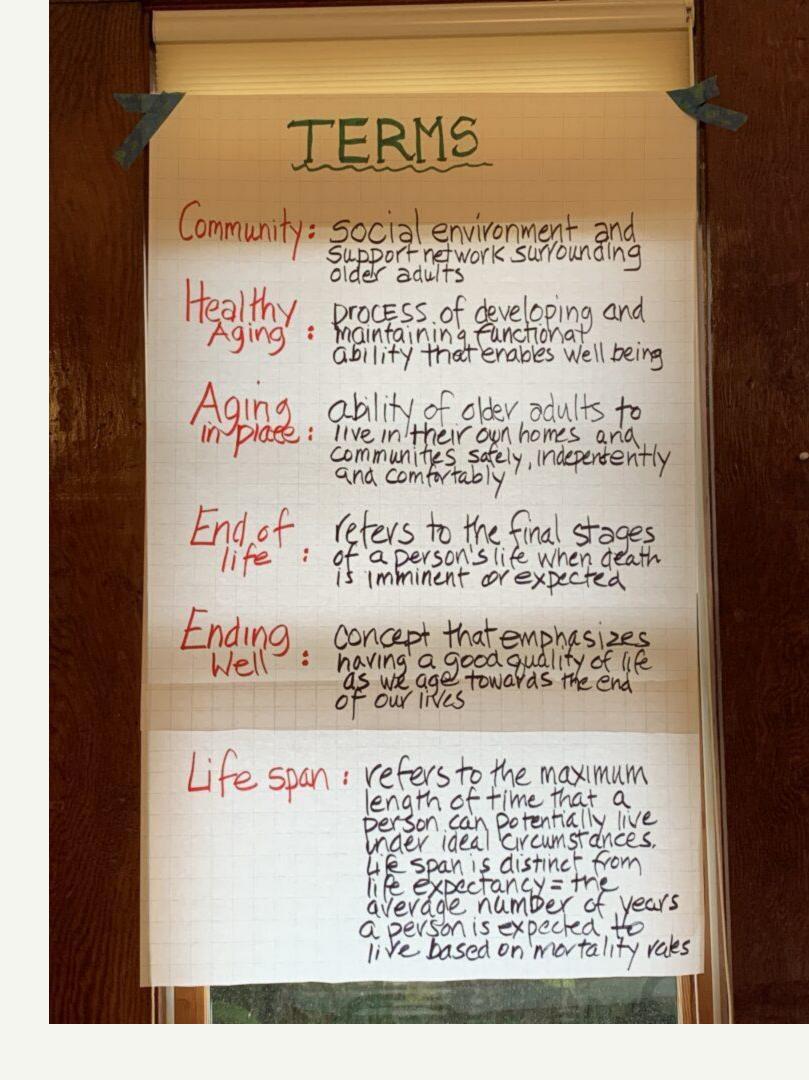


North Coast Drones (FB)

Why Aging with Grace?

1. These are relevant issues for our community. The median age in Cape Meares is 75.

- 1. Little community discussion of these issues and there is a lack of knowledge of options
- 1. We rely on each other as part of our community ethic and the nature of our isolation



Aging with Grace Project Goals and Vision

Goals

- 1. Normalize discussion
- 2. Increase awareness and knowledge

Vision

- Support for aging in place primarily through education and awareness
- ➤ Offer tools for preparing for aging in place and preparing for for end of life

TO: Cape Meares Board

FROM: Bev, Kathy, Narayan, Mimi

RE: Proposal for project

Aging in Place and Preparing for End of Life

Why

- These are relevant issues for our community. The median age in Cape Meares is 75. Twenty-five percent of people in Tillamook County are elderly.
- Little community discussion of these issues and there is a lack of knowledge of options
- We rely on each other as part of our community ethic and the nature of our isolation

Goal

- Normalize discussion of these issues
- Increase awareness and knowledge

Vision

- · Support for aging in place primarily through education and awareness
- Tools for preparing for aging in place and preparing for end of life

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How it Started

- Six member Planning Team created
- Consulted with EOL Margo Lalich
- CMCA Board designated as a CMCA project September 2024 with \$200 allocation (additional allocation of \$600 in 2025 CMCA budget)
- Cape Meares book club read <u>Being</u>

 <u>Mortal</u> by Atul Gawande
- Created Aging with Grace site on CMCA website

CMCA Aging in Place and Preparing for End of Life Project Action Plan 11.8.24

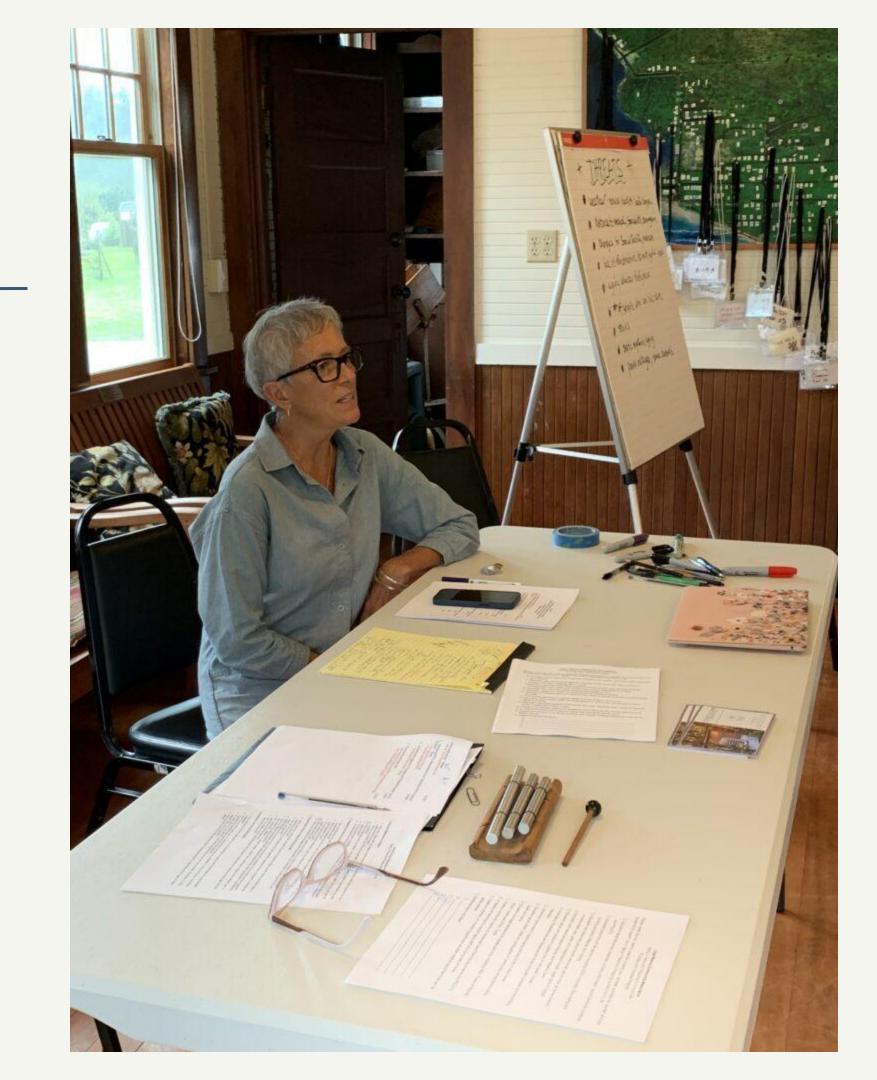
- Grace in Aging: an educational series on aging in place and end of life options
 - January: Estate Planning Overview (wills, trusts, POA, health care POA, etc.)
 Bev and Ann
 - Contact Taylor Kittell, estate planning attorney
 - February: Hospice, palliative care, patient advocacy, Medical Aid in dying, death doulas, emergency preparedness for people with illnesses, slow medicine overview Narayan and Terry
 - Contact Margo Lalich, EOL Collective
 - March: Advanced directives, dementia directives, POLSTs, end of life options (Voluntary Stop Eating and Drinking) overview Mimi and Narayan
 - Tina Castenaras confirmed for March 1, 10-12
 - May be followed by a workshop to fill out forms including making video statements
 - · April: Burial, funeral, celebration and legacy options Peggy and Bev
 - Contact Margo Lalich, EOL Collective, for possible presenters

Next steps:

- First name listed takes the lead in contacting and scheduling speaker and coordinating the event. Note CMCA community calendar for conflicts.
- · Identify title for each presentation and a brief one or two sentence description
- · Reserve community center with Patti
- · Prepare flyer announcing the series, logo ask Kirsten

Started with an Assessment

- ☐ October 26, 2024 introduction to community facilitated by Margo Lalich
 - ☐ Described End of Life Collective
 - □ SWOT analysis
 - ☐ Small group discussions
 - ☐ Survey to identify areas of interest for Planning Team



Activities - Educational Presentations

Educational presentations (videotaped with \$600 grant and widely distributed)

- ☐ January 5: Estate planning
- ☐ February 8: Hospice, palliative care, patient advocacy, death doulas, slow medicine
- ☐ March 1: Advanced directives,

 dementia directives, POLSTs, end of
 life options (Voluntary Stop Eating
 and Drinking), Medical Aid in Dying
- ☐ April 5: Burial options, funerals, celebrations, and legacy options



Researched Local Resources

- Accessibility assessment
- Researched local resources
 - ☐ Tillamook Wellness
 - Adventist
 - ☐ Oregon DHS Senior and Disabilities Services
 - ☐ Tillamook Senior Center
 - ☐ Life flight
 - ☐ In home care options
 - **□** Cemeteries
- Identified how to borrow durable equipment



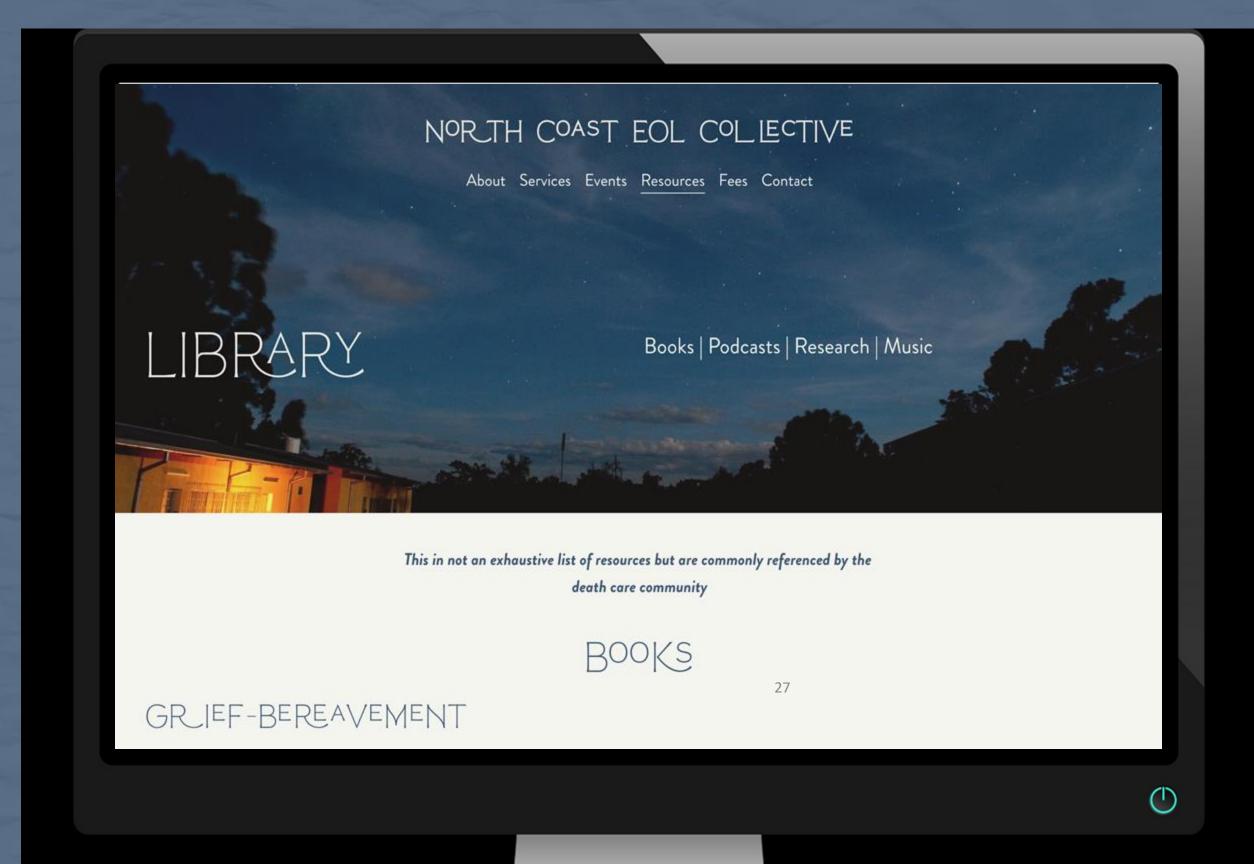
Next Steps

☐ Debrief Community in June Learnings and actions as a result of the educational series? Resource research reports □ Next steps □ Community Reads: Finish Strong by Barbara Coombs Lee □ Patient Advocacy Training to Build Community Capacity ☐ Role of patient advocate and establishing boundaries ☐ Techniques for advocating ☐ Role playing and videos as evidence of intent □ Community walks and dances □ Research possibility of a Cape Meares green burial cemetery **☐ Meet with Volunteer Firefighters**

Still on the Table!

- ☐ Emotional components of aging, behavioral and brain health, loneliness and isolation
- ☐ Technology and Al
- ☐ Alzheimer's and dementia
- ☐ When you can't age in place: choosing an alternative
- ☐ Getting the most from Medicare

- ☐ Conversations with family about aging in place and end of life planning
- ☐ Fall prevention and preparing home for aging
- ☐ Emergency preparedness for elderly in community
- □ Dancing with Aging with Grace
- ☐ Explore establishing a CM green cemetery



RESOURCES

- EOL Considerations
- Palliative and Hospice Care
- Community Resources
- Legacy
- Grief, Bereavement. Trauma
- Pediatric
- Population Specific
- Advanced Care Planning
- Funerals and Burials
- Medical Aid in Dying (MAiD)
- Innovation and Research
- Legal
- Caregiving
- Digital Legacy
- Community Based

Reflections

"At first, I was horrified at attending a death cafe meeting (likely a common occurrence?) but I've come to appreciate your compassion, encouragement, love, and grace handling this otherwise taboo topic. It's vital on our paths of life. Many thanks for your kind words of support and much love" Death Cafe Participant

"I am so truly inspired by what you and your partners have created. I had quite a few new clients in your area in the last month....I really think that is due to all of your amazing work." EOLCOR Volunteer Coordinator

"I have enjoyed seeing some of the work and outreach your group has been providing for the community over the last couple of months. Your group is an incredible resource for planning and navigating the dying and grief journey."

Director, OHSU Body Donation Program

"What an amazing collection of resources! Thank you so much." Client Consultation

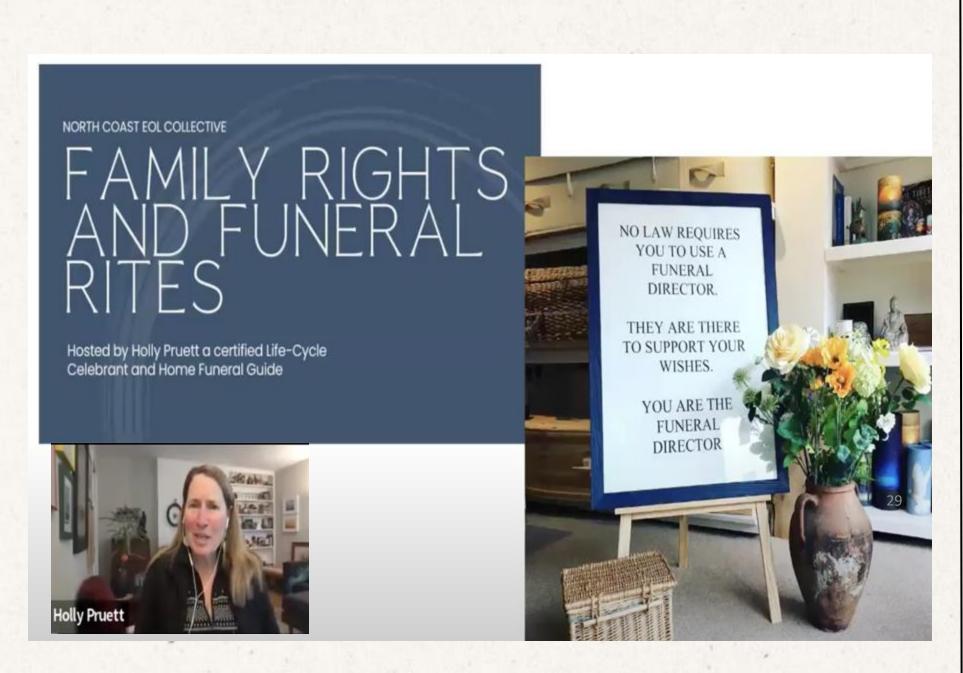
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"I'm so very happy to have met you and learn about the exciting, vital work you are doing!" Resident, EOL Author

Please assist my sibling and me on their path of her last months.... stage IV cancer diagnosis was....they hoped for five years and chemotherapy treatment has been suspended by mutual agreement with their Oncologist." Client Consultation

"It was such a joy to speak with both of you today, thank you so much. The timing on this is perfect for me and I can sense the amazing potential in what you all are offering." Client Consultation

"Incredible! It is an immensely generous gift that was given today. I cannot be more thankful. Already working on my personal financial



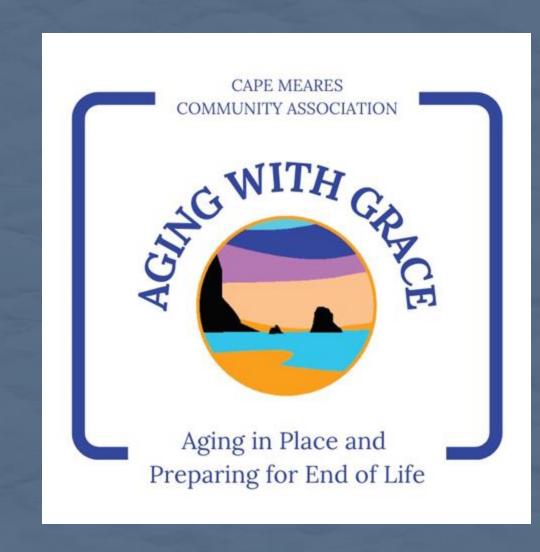
Family Rights and Funeral Rites with Holly Pruett

LIVING WELL

"We know conversations, connection, and learning about death and dying can improve the quality of one's life and create a sense of community around a profound experience we all share."

ENDING WELL

"A just society ensures not only the right to live well—but to die well, with dignity and support."





THANK YOU!



Thank you to the 2025 Forum partners!



















































